

# FACTORing the views of care-givers in research

**Relatives and friends who support people with mental health problems have knowledge and experience that most researchers simply don't have. FACTOR is part of the Mental Health Research Network and puts research teams in touch with carers who are willing to share their expertise, and help researchers plan and carry out trials and projects in a realistic and relevant fashion.**

So when researchers at the Institute of Psychiatry, King's College London, wanted input from carers about a trial testing a support package designed to help people with psychosis take better care of their physical health and cut down on cannabis and alcohol, FACTOR coordinator Geraldine Mason set up a group of carers that met regularly with

representatives of the research team.

Up to seven carers met every two months for a year to discuss the practicalities of the research, focusing particularly on motivation: carers shared their first hand knowledge of the potential difficulties. As a result, the research team decided to enlist the help of family members and friends who are supporting participants on



Geraldine Mason can introduce researchers to care-givers who are willing to get involved in studies.

a daily basis. Carers of people recruited to the trial are now invited to small group meetings where they are given information about the study and can discuss what they can do to help. 'If carers know more about the research, they can encourage the person they are supporting to take part and change to healthier lifestyles,' said Geraldine Mason.

The physical health promotion package seeks to tackle unhealthy lifestyles that can lead to weight problems, high blood pressure, high cholesterol, diabetes and heart disease. The package will be delivered by care coordinators in community mental health teams who will be trained to work with people individually, to try to motivate them to stop smoking, eat more healthily, take more exercise and quit or reduce their intake of cannabis and alcohol. The trial is part of the five-year IMPaCT programme of research funded by the Department of Health's National Institute for Health Research and focusing on the physical health needs of people with mental health problems.

'We wanted to have very active carer comment on our research, about how realistic the proposals were, about issues that are barn-door obvious to carers but that researchers may not have thought of,' said Dr Fiona Gaughran who is leading the trial. 'We wanted carers to comment on and discuss our research, so researchers could listen and adapt protocols and plans in the light of their insights.'

The carers also advised the research team about language, advocating and helping to prepare printed material that was jargon-free and easily understandable for both participants and the care coordinators who would be working with them. They felt it was important for the material used by mental health professionals to be written in plain English to encourage them to speak in the same way. Members of the group helped edit parts of the training manual for care coordinators and information for people recruited to the trial.

Philippa Lowe and Josie Forshaw were both involved in the discussions about the research and spoke about their work at a conference organised by the Mental Health Research



**Philippa Lowe: 'For some of us it's about making a contribution...it's also about getting information... and about improving matters.'**

Network's North and South London regional offices (called Hubs) in February 2010. They both said they had found it rewarding to be able to make a difference.

'Before the conference I asked members of the FACTOR group why they got involved and what the work meant to them,' said Philippa, who supports her son who has schizophrenia. 'For some of us it's about making a contribution, sharing our expertise and knowledge about coping practically and emotionally. It's also about getting information – we are all hungry for information about the condition our children or our other relatives have, about what's caused it, about the prognosis and about the drugs. Some said it's about improving matters, hopefully for our own relative, but if not, then for someone else's.'

Philippa is one of two carers who now attend IMPaCT research team meetings and the FACTOR group has evolved into a London-based Carer Reference Group that meets once a month to discuss not just the IMPaCT trial, but also other Mental Health Research Network (MHRN)-supported

studies that are seeking the views and expertise of family members. Up to nine carers who are part of the Group are paid for their work.

In collaboration with the MHRN's Heart of England regional office, FACTOR is to set up a second Carer Reference Group that will meet in Birmingham.

There are currently 160 carers who are part of FACTOR and get involved with MHRN-supported studies in a number of different ways.

■ For more information about getting input from carers for a research project, contact FACTOR coordinator Geraldine Mason on 0207 848 0643, geraldine.mason@kcl.ac.uk.

If you're a family member supporting someone with a mental health problem and would like to get involved in FACTOR and MHRN-supported studies, contact Geraldine or administrator Lorraine McPherson on 0207 848 0644, mhrnppi@kcl.ac.uk. FACTOR stands for Families/Friends Together in Research.

■ The Mental Health Research Network supports research in England carried out with the help of people who use NHS services and people who work in them. It is part of the National Institute for Health Research and is therefore known as the NIHR MHRN.

Teams of clinical studies officers based at eight regional offices work with mental health professionals in NHS services to recruit people to MHRN-supported studies. They also offer practical support to research teams. FACTOR can advise about the best way of getting carers involved in research projects, and Service Users in Research can put research teams in touch with people with experience of mental health problems who are willing to advise or be involved in studies. To find out more, visit [www.mhrn.info](http://www.mhrn.info)



The Mental Health Research Network is part of the National Institute for Health Research and supports studies in England.

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